

How Can I Connect with Other CIDP Patients?

I've recently been diagnosed with chronic inflammatory demyelinating polyneuropathy (CIDP), and I'm feeling overwhelmed and isolated. How can I find and connect with other patients who are experiencing similar challenges so I don't feel so alone?

Abbie: When managing a chronic illness like CIDP, connecting with others who truly understand your experiences can be incredibly beneficial. One of the most effective ways to find support is by joining online communities such as forums, social media groups or websites specifically for CIDP or chronic illness patients. We invite you to visit our Facebook page (www.facebook.com/IGLivingMagazine) where we focus on the challenges faced by those with chronic illnesses and regularly share information on specific conditions such as CIDP.

These platforms provide a space to share your journey, ask questions and offer mutual support, helping you feel less isolated. Additionally, you might consider connecting with local or national organizations that focus on CIDP or similar conditions. These groups often organize events, webinars and support groups where you can connect with others, either in person or virtually.

Remember that a diagnosis of a chronic illness can feel isolating, but there are resources available to help. If you're feeling alone, don't hesitate to reach out to your healthcare provider for recommendations on local support groups or counseling services. They can often connect you with resources specifically tailored to your needs. You're not alone in this journey. By actively seeking out these connections, you can find a community that offers understanding, encouragement and a shared sense of resilience. At IG Living, our purpose is to help patients navigate their challenges and find the support they need.

How Do I Deal with Hard Knots Forming Under My Skin When Infusing SCIG?

I infuse 10 grams of immune globulin (IG) subcutaneously every seven days over two hours. I have formed hard knots under my skin in so many infusion sites that it is getting difficult to find sites to infuse. I rotate thighs and belly where I can find areas not already knotted up. If I do place a needle in areas with knots, it will not infuse. Is there a solution to this?

Abbie: I spoke with Michelle Greer, RN, IgCN, executive vice president of sales at Nufactor, a specialty infusion company, and she said the formation of hard knots under the skin at infusion sites is a common issue with subcutaneous IG therapy, which can be frustrating when it limits your available infusion sites. Here are some strategies that might help:

- 1) Warm compresses: Before and after infusions, apply a warm compress to the area. This can help increase blood flow, soften the tissue and make it easier to infuse.
- 2) Massage: Gently massaging the area where the knots have formed may help break them down over time. Be careful to avoid excessive pressure, which could cause more irritation.
- 3) Site rotation: Continue rotating your infusion sites as much as possible. Even though you're already doing this, try to map out your sites more precisely, ensuring you're giving each area adequate time to heal before infusing in that site again.
- 4) Smaller volumes, more frequent infusions: Talk to your healthcare provider about possibly infusing smaller amounts more frequently. This can reduce the load on each infusion site, giving your skin more time to recover.
- 5) Needle placement and depth: Consider requesting a nursing visit to ensure you're using the correct technique and needle length for your height and weight. Proper placement can make a big difference in reducing these issues.
- 6) 20% solution: Ask your healthcare provider or specialty pharmacy if you can switch to a 20% IG solution. This higher concentration would mean less volume to infuse, which could simplify your infusions and potentially reduce site reactions.
- 7) Contact your specialty pharmacy: It's also a good idea to reach out to your specialty pharmacy for assistance, which can help ensure you have the best supplies and techniques for your infusions.

Before doing anything, please remember the importance of speaking with your healthcare provider before making any changes.

» **Have a question?** Email us at editor@IGLiving.com.
Your information will remain confidential unless permission is given.



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